OBJECTIVES

- Type 1 diabetes (T1D) management impacts the entire family system.
- Parental distress and burden related to T1D have been well-studied.
- Less is known about the experiences of siblings of youth with T1D.
- Understanding siblings’ role in family quality of life can help inform family-focused interventions, ultimately enhancing family diabetes-related quality of life.
- Research on sibling experiences in other chronic conditions (e.g., autism, cancer) focuses on:
  - parental capacity to tend to other children.
  - psychological adjustment of siblings.
  - interventions targeted at psychological well-being of siblings.
- We expected parents would report difficulty (1) attending to the needs of siblings and (2) siblings experiencing emotional distress related to T1D. Based on clinical anecdotes, we also expected siblings to participate in T1D management.

METHODS & PARTICIPANTS

Parents worry siblings are neglected and feel they have to do different activities.

For this study:
- We used data from n=20 parents who had ≥2 children.
- We reviewed family management and family teamwork codes.
- We developed and applied new codes related to parents’ comments about siblings, using the same iterative process as above.

RESULTS

Three themes emerged relating to parents’ perceptions of siblings’ experiences and their role in family quality of life:

- Siblings Share the T1D Workload
Parents reported that siblings help with T1D management tasks such as noticing highs/lows and administering insulin.

- The Emotional Toll of T1D
Parents noticed siblings experienced frustration, worry, and sadness about diabetes.

- Parental Guilt
Parents expressed concern about siblings having to compromise or forgo activities and sibling needs being neglected.

CONCLUSIONS

- Parents reported siblings of youth with T1D contributed in several ways to family diabetes-specific quality of life:
  - Siblings help with everyday T1D management tasks
  - Siblings experience sadness, burnout, and anxiety related to diabetes
  - Parents worry siblings are neglected and feel they receive less attention
  - Sibling activities and food choices are affected by diabetes
  - The findings suggest identifying and tracking sibling distress and burden may be beneficial and may help care teams provide more holistic care.
  - Families may benefit from resources targeting siblings:
    - Diabetes camps that encourage sibling participation
    - Sibling-inclusive family-centered psychological support services
    - Incorporating sibling needs into presentations at community diabetes education events
  - Further research is needed on quality of life in siblings of youth with T1D.

Research support from: The Leona M. and Harry B. Helmsley Charitable Trust 2015PF-T1D084 (Pis: M. Hilliard & B. Anderson) & NIDDK 1K12DK097696 (Pis: B. Anderson). Questions or inquires may be directed to Marisa Hilliard, Ph.D at marisa.hilliard@bcm.edu or 832-824-7209.